

## REPORT ON THE OUTCOMES FROM THE PUBLIC CONSULTATION ON THE REDESIGN OF END OF LIFE CARE SERVICES AND THE PROPOSED NEXT STEPS

### 1.0 Purpose

- To update the Board on the outcome of the Public Consultation on the Redesign of End of Life Care (EoLC) services.
- To consider the implications of the results of the consultation process on the Business Case

### 2.0 The Business Case

The PCT began a 3 month public consultation on 1<sup>st</sup> October, 2007 to gather stakeholders' views on the plans to develop end of life services. This ran alongside a similar consultation to redesign intermediate care services. The consultation process was supported by the publication of a Business Case which outlined the case for change and specific proposals for changing the balance of investment in services.

The Business Case recognised that the current provision of EoLC services within the PCT was mixed and lacking in defined patient pathways. Services were generally provided for patients with cancer, but not those with other life limiting illness such as heart failure, renal failure and chronic obstructive pulmonary disease. There was, the report indicated, limited resources to provide EoLC services within the community, and with an ageing population who were more likely to suffer from conditions that need EoLC services, demand was likely to continue rise.

The Business Case indicated that while the majority of the population would prefer a home death a large proportion still tend to be admitted to hospital in the last few days and hours of their life. The aim of the PCT was therefore to adapt and commission a range of services for EoLC which, in line with the principles of World Class Commissioning, were owned by clinicians, patients and carers. The newly commissioned services were intended to reduce gaps in service provision and increase choice.

The Business Plan set out proposals to commission a redesigned care pathway for all patients identified as suffering from an advanced disease from which they would die. The Business Case outlined an increased capacity within EoLC services in the community, the cost of which would be offset by a reduction in emergency hospital admissions and individual complex care packages. The redesigned care pathway would also take into account the

diversity of the population to ensure that the cultural, religious and personal beliefs of individuals would be respected and services tailored to take these into account.

The model adopted within the proposal had at its core the desire to ensure that patients were able to express real choice. The approach followed to achieve this is the Kaiser Permanente model and reflects the Pan-Birmingham Palliative Care Network strategy. This care model recognises the complexity of provision required and that unless all elements are in place, the care pathway will not deliver and patients will fall through the gaps into Acute care where they are likely to experience a poor death. Demand has been calculated against a rising older population, the number of people currently dying in hospital and national / local research of peoples preferred option of where they would wish to die.

The Business Case considered three options for the delivery of the redesigned service, these included:

1. Option 1 – District Nurse led EoLC Pathway. This model integrates palliative care with the core role of the District Nurse, at its heart is the supportive care register which is maintained by the patients GP.
2. Option 2 – Is essentially the same as that outlined in option 1, however in place of the District Nursing Team co-ordinating care and independent provider would act as a co-ordinator of services.
3. Option 3 – No change

The business case recognises that there are significant risks in the development of the strategy (Appendix 1) including two high risk areas:

- There being insufficient availability of suitable facilities for additional supportive care beds, and
- That the reduction in emergency & unnecessary admissions into secondary care are not realised

However these risks are seen to be short term if effectively managed.

### **3.0 Public Consultation - Summary of the Outcome**

Responses to the consultation have been analysed independently by the Health Services Management Centre (HSMC). A summary of their conclusions is set out below. The full analysis is attached at Appendix 2. The consultation to gather stakeholders' views on the plans to redesign end of life services drew responses from 25 individuals (17 by questionnaire or email and 8 online responses). There were 14 community responses with 5 of these specifically on the end of life care proposals, including one from the Overview and Scrutiny Committee (OSC) and one from the Public and Patient Involvement Forum (PPIF), and 9 arising from meetings dealing with both

intermediate care and end of life services. There were notes from 10 public meetings and 7 staff meetings.

The majority of respondents to the consultation supported the proposals to expand end of life care services within the community. However comments made highlighted concerns about a lack of capacity among District Nurses to take on the extra responsibility for end of life care. Other worries were about the need for adequately trained staff and the need to ensure that individuals had choices, including the choice to die in hospital or hospice.

All respondents supported the proposals to provide additional supportive end of life care services within the community. Those who commented were very clear about benefits that these additional services would bring. Some raised concerns about the potential financial cost to the patient and their family. There was also some concern about the shortage of people providing social care for vulnerable members of the community. Some made recommendations for improvements, including more night sitting services and faster access to services.

Although the majority of respondents supported the proposals to provide additional holistic alternative therapies, some wanted to make a distinction between different types of support listed under the broad banner of holistic. This was particularly between alternative therapies and spiritual and religious support. These people endorsed NHS funding for alternative therapies but not spiritual and religious support. However it should be noted that there is little evidence from the consultation exercise that the BME community engaged with the exercise in a significant way.

Suggestions made for additional support for individuals in their end of life phase included more health care staff, particularly district nurses and Macmillan nurses but also community nurses, health care assistants, physiotherapists and night sitters. Care which is patient centred was also mentioned, covering aspects such as maintaining dignity, emergency planning and provision, information, psychological support and a culturally sensitive room to say 'goodbye' for those in care. More integration with the local community such as visits from voluntary workers was suggested and also more appropriate accommodation.

Suggestions for additional support for carers included a source of advice and information including help with administration arrangements as a consequence of death, counselling, respite care including a sitting service, financial help, specialist nurses and quicker access to equipment when it was needed.

There were a number of suggestions about the role the voluntary sector could play in providing support to patients and carers including practical support such as help for patients in their own homes, gardening and pet care, help with transport and the cost of transport for shopping and hospital visiting,

and social support, such as befriending, putting people in touch with others and sitting services. One respondent suggested that the voluntary sector was ideally placed to fulfil the role of care co-ordinator. However one or two respondents expressed concerns about more reliance on the voluntary sector.

In response to the question about how the PCT could best ensure that local people with the necessary skills have access to information about job and volunteering opportunities, a number of comments emphasised that more information was needed and that there should be more publicity at community centres and work and pension offices. Adverts in the local press, local retail outlets and internet sites were suggested together with flyers and open evenings. Other suggestions made were about advertising in local health centres and GP surgeries, incorporating advertisements on the Palliative Care website, holding open days and engaging with voluntary and community groups.

In addition to comments in response to the consultation questions, respondents raised several issues. These included concerns about how different categories of patients would be managed in the new proposals and concerns about reductions in beds/inpatient care, including the request that existing beds should not be lost before capacity is built up in the community.

There were also statements about what the PCT must do, such as training in end of life care for all staff having contact with these patients and devolving the allocation of resources to the person managing a patients' end of life care.

One or two stakeholders felt left out of the consultation process, for example Marie Curie Nursing Services and St. Giles Hospice.

The OSC initially had concerns about running two consultations at the same time (on Intermediate Care & the End of Life Care Business Case) but were satisfied that a clear distinction was made between the two and considered that overall the consultation process was appropriate. However, they felt that greater clarity could have been achieved on the consultation questions and consultation document. They also suggested that on a number of occasions a few members of the public dominated the discussions and some slides were difficult to read.

The OSC also made the comment that the Trust had not been proactive in establishing a way of feeding back to participants. They also felt that greater clarity could have been achieved on the consultation questions and consultation document.

## 4.0 Implications of the consultation

It is clear from the independent analysis of the responses to the consultation produced by the Health Service Management Centre (HSMC) of the University of Birmingham, a summary of which is included above, that all but one of the respondents of the consultation supported the proposals to expand end of life care services within the community. With this background, it is therefore important to address the concerns which were expressed during the consultation, and how these concerns may effect the assumptions, conclusions and recommendations contained in the Business case.

The concerns expressed during the consultation can be broken down into a number of key areas:

- Funding - *'This is a good idea, but will the PCT really make the funds available to make it work, especially in the early stages?'*
- Service reduction – *'Bed numbers must not be reduced before the community services are available.'*
- Capacity – *'We do not believe that the District Nurses have the capacity to be able to co-ordinate and deliver this extra service'*
- Training – *'Will staff be sufficiently trained to deliver this complex and sensitive service?'*
- Choice – *'Will we really be given a choice, including the choice to die in hospital or the hospice?'*
- Flexibility – *'Will the service be flexible enough to respond to our perhaps very different needs?'*
- Practical support – *'Will the service be able to respond to my practical needs like walking the dog, doing the garden etc, and not just to my physical and emotional needs?'*
- The whole community – *'Will the service be able to respond to the needs of the whole community, recognising our different religious and cultural backgrounds?'*

Whilst the language used may be different, these concerns are also raised in the Business Case which makes comparisons between the proposal and comments easier to deal with, however it may be useful to reflect of these common concerns.

- Funding – The Business Case does recognise the need to increase investment in community services. There is no intention to renege on this commitment as to do so would undermine the whole philosophy of this plan.
- Services reduction – The PCT has indicated that it is likely that there will a time lag before a reduction can be seen in emergency and inappropriate admissions. It is for this reason that they have indicated there has to be an investment in new services before the current services are reduced.

This commitment is not as clear concerning the proposed disinvestment in Nursing Home Placements, and the Nightsitting service provided by Marie Curie. It is important that the PCT makes clear that these services will not be reduced before the alternative services are in place and are seen to be working.

- Capacity – The Business Case recognises that there may be increased service demands on District Nursing when the new model is introduced, it does, however, indicate that this will be kept under review on a monthly basis for the first six months. It is clear from the Business Case that because this is a new service using a model as yet untried, the balance of investment in the various aspects of the new service will need to be flexible, especially during the initial operating stages. The PCT will need to consider how it achieves this whilst recognising that the effectiveness of the service depends on speedy reaction to demand especially when patient's conditions change.
- Training – There are clear statements within the Business Case supporting the need for staff to be appropriately trained, including GP's and District Nurses. The Business Case also identifies a sum of £10,000 to support training. There will be a need to produce a detailed workforce plan which clearly identifies the extent of the training need as part of the detailed specification.
- Choice – The primary objective of the Strategy is to ensure that patients have real choice concerning how and where they are treated. The clear concern is that the service needs to be flexible enough to respond to this challenge. In many areas of healthcare delivering choice may be less problematic because individual choice is something that can be planned. In End of Life Care a patient's condition may change rapidly and at night or during a weekend, the delivery of choice in these circumstance is only possible if the service as been able to fully brief patient and carers on the likely progression of the illness, the options available at each stage and the support that will be available.
- Flexibility – Whilst the PCT's intention to delivery a flexible service is implicit throughout the Business Case, the term is only used once in the document in reference to the White Paper '*Our health, our care, our say*'.
- Practical Support – The Business Case identifies the need to commission practical support for patients and carers, there is no clear indication of how this is funded.
- The Whole Community – The Business Case is clear in indicating that the PCT wishes to develop a service which recognises and is sensitive to the needs of all its population, specifically different religious, spiritual and cultural needs. However, as indicated above, there was little engagement with the BME community during the consultation process. There will need

to be a clear strategy to ensure that the BME community is effectively engaged as this service is developed.

It is clear from the results of the consultation that those who participated had a clear understanding of the difficulties in developing a service that can effectively achieve the aspirations set out within the Business Case. As indicated above, much of the concern reflects an acknowledgement that providing such a service, which responds to individual choice and the basic needs of patients and their carers is complex to organise. One could summarise the concerns expressed in one sentence:

*'We understand what you wish to do, but can you really do it?'*

Such a reassurance can only really be provided in delivery.

## 5.0 Conclusion

There is general support for the range of proposed improvements in End of Life Care outlined in the consultation document and the Business Plan.

The PCT remains committed to the development of new services up front before expecting to see any reduction in inappropriate hospital admissions.

Critically the consultation had put forward two options for the co-ordination of care and the biggest concerns raised during the consultation was the capacity of District Nursing services to undertake this role and we propose to review this option as we move into the next phase of development of the service

A further option would be for the PCT to commission the whole service as a single tender, requiring the successful tenderer to manage all of the sub contracts not just acting as a co-ordinator of service as outlined in Option 2. The management of the whole supply chain would reflect a number of the 'headlines' in World Class Commissioning, including the requirement to stimulate the market.

## 6.0 Recommendations

That the PCT Board

1. Receive this report on the outcome of the public consultation on the Redesign of End of Life Care
2. Endorse the original proposals to develop a range of community based care models for End of Life Care

3. Note the intention, in developing the new models, to review the options for the role of care co-ordination in the light of the concerns and reservations expressed during the consultation about the capacity of District Nursing Services to undertake this role and to explore alternative commissioning and provider models

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## Appendix 1

### Risk Register

Risk	High / Med / Low / Risk	Actions to Manage Risk
The assumptions around demand and capacity within the business case are incorrect.	<b>Medium</b>	The PCT will have to continue to monitor admissions to hospitals resulting in death within 14 days of admission to ensure adequate capacity within the community. In addition, utilisation of community services and bedded facilities will have to be monitored to ensure there is not over-provision of services.
That GP's will fail to update their Gold Standard Framework Register	<b>Low</b>	To be monitored through the PCT's performance management framework for GP's.
People in BEN PCT would actually chose to die in hospital	<b>Low</b>	This is unlikely given the level and type of research undertaken on the subject.
The demand on District Nurses is greater than their capacity for provision of care	<b>Medium</b>	Through close monitoring of workloads in initial 6 months any need for additional capacity can be identified / quantified and addressed at an early stage
Insufficient availability of suitable facilities for additional supportive care beds	<b>High</b>	In the short-term this is likely, however, in the longer-term, with the opportunity to occupy the Councils, next 2 Care Centres the risk will significantly drop.
Reduction in emergency & unnecessary admissions into secondary care not realised	<b>High</b>	In the short-term this is likely due to necessary changes in clinical approach, and the possibility that it may take time to commission all the community services needed to deliver the new model of care.
Cost of drugs in primary care is prohibitive	<b>Low</b>	As the savings from emergency and unnecessary admissions are significant, it is unlikely that the additional cost of drugs in primary care will be greater than the savings made.

UNIVERSITY OF  
BIRMINGHAM

**Report of a public consultation on  
proposals for developing end of life care  
services across Birmingham East and North  
Primary Care Trust**

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## Table of Contents

**1. Summary**

**2. Introduction**

**3. Background**

**4. Analysis**

**5. Responses**

**6. Conclusions**

**7. Appendix**

## **1. Summary**

Birmingham East and North Primary Care Trust's consultation to gather stakeholders' views on the plans to redesign end of life services drew responses from 25 individuals (17 by questionnaire or email and 8 online responses). There were 14 community responses with 5 of these specifically on the end of life care proposals, including one from the Overview and Scrutiny Committee and one from the Public and Patient Involvement Forum, and 9 arising from meetings dealing with both intermediate care and end of life services. There were notes from 10 public meetings and 7 staff meetings.

The majority of respondents to the consultation supported the proposals to expand end of life care services within the community. However comments made highlighted concerns about a lack of capacity among District Nurses to take on the extra responsibility for end of life care. Other worries were about the need for adequately trained staff and the need to ensure that individuals had choices, including the choice to die in hospital or hospice.

All respondents supported the proposals to provide additional supportive end of life care services within the community. Comments identified expected benefits that these additional services would bring but also concerns about the cost to the patient and family and the shortage of people providing social care for vulnerable members of the community. Some made recommendations for improvements, including more night sitting services and faster access to services.

Although the majority of respondents supported the proposals to provide additional holistic alternative therapies, some wanted to make a distinction between different types of support listed under the broad banner of holistic. This was particularly between alternative therapies and spiritual and religious support. These people endorsed NHS funding for alternative therapies but not spiritual and religious support.

Suggestions made for additional support for individuals in their end of life phase included more health care staff, particularly district nurses and Macmillan nurses but also community nurses, health care assistants, physiotherapists and night sitters. Care which is patient centred was also mentioned, covering aspects such as maintaining dignity, emergency planning and provision, information, psychological support and a culturally sensitive room to say 'goodbye' for those in care. More integration with the local community such as visits from voluntary workers was suggested and also more appropriate accommodation.

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In addition to comments in response to the consultation questions, respondents raised several issues. These included concerns about how different categories of patients would be managed in the new proposals and concerns about reductions in beds/inpatient care, including the request that existing beds should not be lost before capacity is built up in the community.

There were also statements about what the PCT must do, such as training in end of life care for all staff having contact with these patients and devolving the allocation of resources to the person managing a patients' end of life care.

One or two stakeholders felt left out of the consultation process, for example Marie Curie Nursing Services and St. Giles Hospice.

The OSC initially had concerns about running two consultations at the same time but were satisfied that a clear distinction was made between the two and considered that overall the consultation process was appropriate. However, they felt that greater clarity could have been achieved on the consultation questions and consultation document.

## **2. Introduction**

Birmingham East and North Primary Care Trust (BEN PCT) began a public consultation to gather stakeholders' views on the plans to develop end of life services on 1<sup>st</sup> October, 2007. This ran alongside a similar consultation to redesign intermediate care services.

Both consultations ended on 11<sup>th</sup> January 2008 and BEN PCT commissioned the Health Services Management Centre at Birmingham University to carry out the analysis of responses. This report provides details of the findings.

The consultation included the following elements:

1. Consultation documents were sent out to 54 Birmingham City Council Councillors and Members of Parliament within the Trust's locality
2. Consultation documents were sent out to 694 patients who had used intermediate care services in the six months before the launch date of the consultation
3. Consultation documents were sent to relevant statutory and third sector organisations, including commissioning directors and chief executives of other NHS organisations
4. The PCT Communication and Involvement team coordinated 10 public meetings facilitated by staff from the Commissioning Department and Operational Services in the geographical area covered by the PCT
5. Presentations about the redesign proposals were delivered at 18 community group meetings. These included the Local Authority Overview and Scrutiny Committee and the Public and Patient Involvement Forum
6. Staff briefings took place at Sutton Cottage Hospital, Grange Road Nursing Home, Berwood Court Nursing Home and John Taylor Hospice

Responses were received in a variety of formats:

- The online questionnaire on the PCT's website
- Freepost using the questionnaire in the consultation documents
- Letter
- Email
- Recorded at meetings

The next section provides brief details of the consultation documents, before the way in which the responses were analysed is described in section 4. The findings from the analysis are presented in section 5 and conclusions are drawn in section 6.

### **3. Background**

The consultation document states that currently end of life care services provided by BEN PCT are varied and individuals do not have access to the same range of services. Many people who would choose to die in their own home actually die in hospital or nursing homes.

The PCT intends to redesign end of life care services to ensure a wider range of community support is available so that more people can die in the place they choose. This entails the investment of significant financial resources into providing additional community-based services for people.

Proposals include additional teams of allied health professionals, expansion of the Hospice at Home services, additional community based supportive and holistic services and 36 additional community based beds for people in their end of life care phase.

The consultation document included a questionnaire that asked for responses to eight questions. These included questions about the proposals, about the kind of additional support that should be provided to individuals and their carers, about how the PCT could make local people aware of job and volunteer opportunities and for respondents' socio-demographic details.

The following section describes how the responses to the consultation were analysed

#### **4. Analysis**

The responses were divided into four categories:

1. returned questionnaires and individual letters/emails
2. responses to the online survey
3. community responses and notes from community meetings
4. notes from public meetings
5. notes from staff briefings

The returned questionnaires and responses to the online survey were subjected to both quantitative and qualitative analysis. Responses to each question were counted and the comments were themed into categories. Community responses and notes were related to specific items in the questionnaire or themed into additional categories.

The next section presents an analysis of the responses and more detailed analysis tables can be found in the appendix.

#### **5. Responses**

This section begins with details of the number and type of responses received and the socio-demographic details of online and questionnaire respondents. The findings for each question are then reported, followed by additional themes that occurred in the responses. Finally respondents' comments on the consultation process are described.

A total of 17 individual responses were received, with 15 of these completed questionnaires, and two emails. There were 8 female and 4 male responses (2 non-response). All but one were aged 60 or over, with the exception being in the 40-49 category. All who responded (15) indicated that they were White.

There were 8 online responses, of which 2 were male and 5 female (1 non-response). Of these, 2 were patients and 5 were staff (1 non-response). Their ages were younger than the individual responses with 3 in the 40-49 category, 2 in the 60 and over, and one each in 50-59 and 30-39. The majority (6) were white with 1 Black-Caribbean.

There were 14 community responses with 5 of these specifically on the intermediate care proposals, including one from the Overview and Scrutiny Committee and one from the Public and Patient Involvement Forum, and 9 arising from meetings dealing with both intermediate care and end of life services. There were notes from 10 public meetings and 7 staff meetings.

**Question 1: Do you support the proposals to expand end of life care services within the community?**

There were 16 individual responses to this question, of which 15 supported the proposals and one did not. All 8 of the online respondents supported the proposal.

**Comments on questionnaires**

There were three main themes arising from the comments on the individual questionnaires. These were:

1. Concern over lack of capacity amongst District Nurses to take on the extra responsibility in end of life care in the community

*I fail to see how District Nurses can take on this NEW role of being central to the End of Life Care Plan without considerable enhancement of the team which will have funding implications. What part of their present duties can they relinquish?*

*I would be more in favour of the development of a specialist team of nurses involved mainly in end of life care services, rather than a shift to the use of overworked District Nurses.*

*On p.29 there is a mention that the District Nursing Manager does not consider that there would be a requirement for extra District Nursing capacity as this should be part of their core responsibility. I do not agree – if the approach is to enable more patients to die at home and reduce admissions to hospital, there is bound to be increased burden on the District Nurses who it is determined will be overseeing this process*

2. Support for the proposals to allow more people the choice to die at home if they want to because of benefits it brings

*I think this is a good idea and should be made available to all that need it*

*This is vital if we are going to give people choices by asking about Preferred Places of Care and Advanced Care Planning*

3. Need for adequately trained staff

*I would like to be certain that any additional beds for end of life care are supported by adequately trained staff*

**Comments/responses from public meetings and community and staff responses**

Of the 12 responses from the community, two responded in a systematic way to each of the questionnaire items and the rest responded generally to the subject of end of life care or

raised issues in relation to one or two items. The two that responded to this question both supported the proposal.

The main additional category of comments from this source was about the need to ensure that individuals had choices, including the choice to die in hospital or hospice.

*End of life care should still be delivered in hospitals, hospices and nursing homes for those people who feel safer in such an environment; those without carer support; and those whose carers care not willing or able to look after them*

*Allow for potential that many patients/carers would not feel comfortable dying at home – allow this choice. Acknowledge cultural/racial differences eg feelings of Muslim community about dying at home.*

*Facilities should be available for people with no relatives to care for them particularly stroke patients*

*What is needed is an organisation that can act as a ‘clearing house’ for all the strands/problems that patients and carers are trying to manage such as treatment, employment, pain management, benefits, support, childcare responsibilities, respite care etc. Patients and their families/carers need to have choices about their treatment and care, where they want to die, and how they want to live so that services can be tailored to meet their needs and preferences.*

**Question 2: Do you support the proposals to provide additional supportive (eg domestic and carer support, night sitting etc) end of life care services within the community**

16 of the 17 individual respondents answered this question and all supported the proposals. All 8 respondents supported the proposals.

**Comments on questionnaires**

There were three main themes identified from the comments made. These were:

1. Expectations of the benefits it will bring

*This service will help lot of old aged living either single or partners in isolation and cold. No good neighbours to keep an eye*

*These services would be invaluable to carers but must be dependable and readily accessed.*

*Without this support patients are admitted to hospital at End of Life unnecessarily*

## 2. Concerns

*I am concerned about the cost to the patient and family if they have to pay for these services*

*I am concerned that there appears to be a shortage of people capable of undertaking the task of providing social care for vulnerable members of our community in a sensitive and reliable way. Sensitivity and reliability should be priorities*

## 3. Recommendations

*Night sitting service needs to be heavily invested in as this service is in great demand but very little night support available in the community*

*Make sure that all who need care and help get it without having to wait too long*

### **Comments/responses from public meetings and community and staff responses**

The two that responded to question 2 both supported the proposal. One comment was made about this question:

*Use of domestic staff in a responsible and rewarding way, as these members of staff will have daily close contact with service users and relatives. Domestic staff should have clear professional boundaries between nursing care and social care home help and support. Relatives and carers should be fully aware of the service being offered ...to resolve issues of contention between nursing and social care.*

### **Question 3: Do you support the proposals to provide additional holistic (eg alternative therapies, spiritual and religious support, access to support groups) end of life care services within the community?**

Of the individual responses, 13 supported the proposals, 1 did not and there were 3 non-responses. All 8 respondents supported this proposal

### **Comments on questionnaires**

Some respondents made a distinction between different types of support listed under the broad banner of holistic, particularly between alternative therapies and spiritual and religious support. These people endorsed NHS funding for alternative therapies but not spiritual and religious support.

*I support additional holistic therapies where it can be shown that they have a positive influence on mental health and well being. In relation to faith or spiritual support, I am against NHS funding and resources being allocated to faith groups to provide*

*these services as it is already part of their function to provide them free of cost. The PCT does not provide circumcision on religious grounds and thus to provide faith or spiritual support paid for by the PCT would set a potential precedent*

*There should be opportunities for individual needs to be ascertained, not only physical, practical but spiritual – and not one size fits all. However it will mean a careful and tight control in appointing professionals with appropriate status to avoid any suggestion of waste of funding*

*Alternative therapies wonderful as long as patient/family agree. Spiritual and religious is fine only when done with care and agreement with all concerned*

### **Comments/responses from public meetings and community and staff responses**

Comments were generally supportive:

*Anything that puts the patient at ease will help their carers and relatives towards a feeling of confidence in the service that things are being done appropriately and professionally. The patient should make that informed choice themselves where possible.*

### **Question 4: What sort of additional support would you like to have available for individuals in their end of life phase?**

Different types of support were suggested:

1. More health care staff – district nurses and Macmillan nurses particularly, but also community nurses, health care assistants and physiotherapists, night sitters. Hospice at Home.
2. Care which is patient centred – maintaining dignity, emergency planning and provision, information, psychological support
3. More integration with the local community – visits from voluntary workers
4. More appropriate accommodation
5. Legal change to allow assisted suicide

### **Comments/responses from public meetings and community and staff responses**

Two additional issues were mentioned:

6. A review of medication for those in their end of life phase. (*For example, for those with only a few days or weeks to live, a reassessment of the required medication by the service user, their carer, doctor and/or district nurse could make their last days more pleasurable and less restrictive*)

7. When in care, a room (culturally sensitive) where relatives could meet to say goodbye in a private and dignified way.

**Question 5: What sort of additional support would you like to have available for carers of individuals in their end of life phase?**

The following types of additional support could be identified:

1. Source of advice and information, so that there is “someone they can call for help at any time of the day or night.” This could include talking to “people who have gone through this already”
2. Respite care, including sitting service
3. Financial help if needed
4. Specialist nurses
5. Equipment quickly when needed

**Comments/responses from public meetings and community and staff responses**

Additional suggestions were

6. The carer should be given additional support such as respite, training (for example in manual handling) and counselling wherever necessary
7. The offer of counselling and administrative support to help with inevitable arrangements following as a consequence of death

**Question 6: What role could the voluntary sector play in providing support to patients and carers in their end of life care phase?**

Suggestions from individual and online responses included practical support such as help for patients in their own homes, gardening and pet care, help with transport and the cost of transport for shopping and hospital visiting, and social support, such as befriending, putting people in touch with others and sitting services.

One or two comments expressed concerns about more reliance on the voluntary sector:

*I am opposed to the increase in emphasis on the voluntary sector as the service provided by the voluntary sector can be erratic and is not subject to enough statutory control and inspection for quality and consistency*

*Dovetailing where the PCT does not have the expertise or resources eg hospice ethos or infra structure. But this should not be an escape route for avoidance of funding*

### **Comments/responses from public meetings and community and staff responses**

Two additional suggestions were made:

1. The voluntary and community sector would be ideally placed to fulfil the 'key worker' care co-ordination
2. Support groups with optional attendance and support in person, telephone or administrative support

### **Question 7: How could the PCT best ensure local people with the necessary skills have access to information about the job and volunteer opportunities that would be generated through redesign and relocation of services?**

The comments on individual questionnaires emphasised that more information was needed and that there should be more publicity at community centres and work and pension offices. Adverts in the local press, local retail outlets and internet sites were suggested together with flyers and open evenings.

Online responses included advertising through the health news letter and by distribution in local health centres and GP surgeries. Also

*Incorporate in some way with Pan Birmingham Palliative Care Network Living Well to the End of Life. Local advertising newspapers and radio. Advertise on the Palliative Care website – accessed by patients, carers and general public*

Responses from public meetings and community and staff included:

1. Holding open days with local community leaders that influence all ethnic groups, use media, flyers. Embrace champions with whom the local community might identify to promote awareness about new job opportunities and introduce the facility to all the community
2. Engage with voluntary and community groups to provide information about the available services and encourage volunteering opportunities.

### **Other main issues raised in the responses**

These could be divided into the following categories:

1. Concerns about how different categories of patients would be managed in the new proposals (eg patients with dementia, children) and the fact that inequalities need to be addressed among different categories of patients, not just in relation to where people live
2. Concerns about reductions in beds/inpatient care, including the request that existing beds should not be lost before capacity is built up in the community, also the question *“Is the PCT trying to push palliative care out of hospitals?”* and the comment *“Is the strategy being target driven particularly about the very ambitious moves to reduce the numbers who die in acute care – concern that if this is a mandatory requirement it will lead to patients either being refused admission or discharged inappropriately in order to meet the target”*
3. Statements about what the PCT must do: training in end of life care for all staff having contact with these patients; devolving the allocation of resources to the person managing a patients’ end of life care; exploring deaf awareness training for all staff. Also comments on current services, such as equipment is often not collected yet there is a shortage and if BME groups have patients in current services /hospices they are often isolated within a non BME group and feel alone and often frightened
4. Statements about the need for joint assessment processes to avoid distress and inconvenience to patients and to enable them to follow up in a co-ordinated way
5. One or two stakeholders feeling left out of the consultation process. For example Marie Curie Nursing Services would have preferred to be involved in decisions early rather than find out through the consultation that there is a proposal to disinvest in their services. Current service provision by them also appears to be omitted in the section dealing with this. St. Giles Hospice is concerned that factual errors misrepresenting the type, level and cost of services provided to the community of North Birmingham by the Hospice have not been rectified
6. Comments about hospice care: there is a need for as hospice in Bordesley Green to ensure adequate facilities and St. Mary’s hospice is already co-ordinating individual care and the service is excellent

### **Comments on the consultation process**

The OSC initially had concerns about running two consultations at the same time but were satisfied that a clear distinction was made between the two and considered that overall the consultation process was appropriate. However, they felt that on a number of occasions a few members of the public dominated the discussions and some slides were difficult to read.

The OSC also made the comment that the Trust had not been proactive in establishing a way of feeding back to participants. They also felt that greater clarity could have been achieved on the consultation questions and consultation document as *“nowhere in the document was the respondent asked for their preference over the three options put forward.”*

## 6. Conclusions

All but one of the respondents to the consultation supported the proposals to expand end of life care services within the community. However comments made highlighted concerns about a lack of capacity among District Nurses to take on the extra responsibility for end of life care. Other worries were about the need for adequately trained staff and the need to ensure that individuals had choices, including the choice to die in hospital or hospice.

All respondents supported the proposals to provide additional supportive end of life care services within the community. Comments identified expected benefits that these additional services would bring but also concerns about the cost to the patient and family and the shortage of people providing social care for vulnerable members of the community. Some made recommendations for improvements, including more night sitting services and faster access to services.

Although the majority of respondents supported the proposals to provide additional holistic alternative therapies, some wanted to make a distinction between different types of support listed under the broad banner of holistic. This was particularly between alternative therapies and spiritual and religious support. These people endorsed NHS funding for alternative therapies but not spiritual and religious support.

Suggestions made for additional support for individuals in their end of life phase included more health care staff, particularly district nurses and Macmillan nurses but also community nurses, health care assistants, physiotherapists and night sitters. Care which is patient centred was also mentioned, covering aspects such as maintaining dignity, emergency planning and provision, information, psychological support and a culturally sensitive room to say 'goodbye' for those in care. More integration with the local community such as visits from voluntary workers was suggested and also more appropriate accommodation. One person suggested legal change to allow assisted suicide and another thought that a review of medication was also important.

Suggestions for additional support for carers included a source of advice and information including help with administration arrangements as a consequence of death, counselling, respite care including a sitting service, financial help, specialist nurses and quicker access to equipment when it was needed.

There were a number of suggestions about the role the voluntary sector could play in providing support to patients and carers including **practical support** such as help for patients in their own homes, gardening and pet care, help with transport and the cost of transport for shopping and hospital visiting, and **social support**, such as befriending, putting people in touch with others and sitting services. One respondent suggested that the voluntary sector was ideally placed to fulfil the role of care co-ordinator. However one or two respondents expressed concerns about more reliance on the voluntary sector.

In response to the question about how the PCT could best ensure that local people with the necessary skills have access to information about job and volunteer opportunities, a number

of comments emphasised that more information was needed and that there should be more publicity at community centres and work and pension offices. Adverts in the local press, local retail outlets and internet sites were suggested together with flyers and open evenings.

Other suggestions made were about advertising in local health centres and GP surgeries, incorporating advertisements on the Palliative Care website, holding open days and engaging with voluntary and community groups.

In addition to comments in response to the consultation questions, respondents raised several issues. These included concerns about how different categories of patients would be managed in the new proposals and concerns about reductions in beds/inpatient care, including the request that existing beds should not be lost before capacity is built up in the community.

There were also statements about what the PCT must do, such as training in end of life care for all staff having contact with these patients and devolving the allocation of resources to the person managing a patients' end of life care.

One or two stakeholders felt left out of the consultation process, for example Marie Curie Nursing Services and St. Giles Hospice.

The OSC initially had concerns about running two consultations at the same time but were satisfied that a clear distinction was made between the two and considered that overall the consultation process was appropriate. However, they felt that on a number of occasions a few members of the public dominated the discussions and some slides were difficult to read.

The OSC also made the comment that the Trust had not been proactive in establishing a way of feeding back to participants. They also felt that greater clarity could have been achieved on the consultation questions and consultation document.

## 7. Appendix

### **QUESTION ONE**

<b>Question</b>	<b>Response</b>	<b>Comments</b>
<p><b>Do you support the proposals to expand end of life care services within the community?</b></p>	<p>16 responded to this question, of which 15 answered YES and one NO</p>	<ol style="list-style-type: none"> <li>1. I think this is a good idea and should be made available to all that need it</li> <li>2. To access the community services will give a person a better outlook on life</li> <li>3. Save lot of duplication work and money</li> <li>4. I would like to be certain that any additional beds for end of life care are supported by adequately trained staff</li> <li>5. I have read the Business Case document and applaud the proposals as set down since it seems to express the perceived needs of patients at the end of their lives as far as they go...however...I fail to see how District Nurses can take on this NEW role of being central to the End of Life Care Plan without considerable enhancement of the team which will have funding implications. What part of their present duties can they relinquish? My biggest concern is about communication and careful recording from start to finish...I write out of experience of a misdiagnosis resulting from one hospital not knowing of a different cancer episode in another hospital and time being lost during investigations (patient story included – not local hospital experience but relevant to end of life care)</li> <li>6. I would be more in favour of the development of a specialist team of nurses involved mainly in end of life care services, rather than a shift to the use of overworked District Nurses.</li> <li>7. On p.29 there is a mention that the District Nursing Manager does not consider that there would be a</li> </ol>

		<p>requirement for extra District Nursing capacity as this should be part of their core responsibility. I do not agree – if the approach is to enable more patients to die at home and reduce admissions to hospital, there is bound to be increased burden on the District Nurses who it is determined will be overseeing this process</p> <p>8. We must make every effort to ensure all help is given to those who need care</p> <p>9. I have tried to give answers to you but I'm afraid of what to say- this is a wonderful thing you are doing for people who are ill</p>
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Online response to Q1:

8 people responded online and all of these supported the proposal.

**Online respondent comments**

Respondent	Comment
1	This is vital if we are going to give people choices by asking about Preferred Places of Care and Advanced Care Planning
2	Care and support at this stage of any life or illness is very important to help the patient keep their dignity
3	Definitely hospice beds are limited, many patients wish to remain at home and need care support to do so

**Themes from comments on questionnaires**

4. Concern over lack of capacity amongst District Nurses to take on the extra responsibility in end of life care in the community
5. Support for the proposals to allow more people the choice to die at home if they want to because of benefits it brings
6. Need for adequately trained staff

**Comments/responses from public meetings and community and staff responses**

Of the 12 responses from the community, two responded in a systematic way to each of the questionnaire items and the rest responded generally to the subject of end of life care or raised issues in relation to one or two items.

The two that responded to this question both supported the proposal. The following comments relating to the question were made:

Response	Comment
1	Co-ordination of these services should not fall to the District Nurse. End of life care should still be delivered in hospitals, hospices and nursing homes for those people who feel safer in such an environment; those without carer support; and those whose carers care not willing or able to look after them
2	Given the nature of individuals' own mortality and having witnessed some powerful emotions, we feel these new enhanced proposals vastly improve upon existing services to date. If mortality rates increased would there be enough scope to relieve pressure on existing staff – there must be a robust business plan that will withstand such unpredicted workload.
3	We share the PCT's view that the current service provision for this group of patients is inadequate and that far too many people die in hospital who would prefer to die in the community, ideally in their own home. We are keen to support proposals that lead to a shift into the community
4	...people at the end of their life should be treated as 'special people' and there is an urgent need to develop services that enable more people, regardless of diagnosis to die at home if that is their preference
5	Allow for potential that many patients/carers would not feel comfortable dying at home – allow this choice. Acknowledge cultural/racial differences eg feelings of Muslim community about dying at home. Concerns about district nursing capacity and capabilities
6	Pressure on district nurses to coordinate care
7	There is a language barrier with district nurses when dealing with some patients in end of life
8	Facilities should be available for people with no relatives to care for them particularly stroke patients
9	What is needed is an organisation that can act as a 'clearing house' for all the strands/problems that patients and carers are trying to manage such as treatment, employment, pain management, benefits, support, childcare responsibilities, respite care etc. Patients and their families/carers need to have choices about their treatment and care, where they want to die, and how they want to live so that services can be tailored to meet their needs and preferences.

**QUESTION 2**

Question	Response	Comments
<b>Do you support the proposals to provide additional supportive (eg domestic and carer support, night sitting etc) end of life care services within the community?</b>	16 of the 17 individual respondents answered this question and all answered YES	1. Most older people would prefer to stay at home in their own bed with adequate care from the nursing profession until the end 2. Excellent, not before time 3. This service will help lot of old aged living either single or partners in

	<p>isolation and cold. No good neighbours to keep an eye</p> <p>4. I am concerned that there appears to be a shortage of people capable of undertaking the task of providing social care for vulnerable members of our community in a sensitive and reliable way. Sensitivity and reliability should be priorities</p> <p>5. I am concerned about the cost to the patient and family if they have to pay for these services</p> <p>6. These services would be invaluable to carers but must be dependable and readily accessed.</p> <p>7. Make sure that all who need care and help get it without having to wait too long</p>
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Online response to Q2:

All 8 respondents supported the proposals

**Online respondent comments**

Respondent	Comment
1	Without this support patients are admitted to hospital at End of Life unnecessarily
2	Anything to help ease the load on a family, or to make life easier for a patient who may be on their own
3	Night sitting service needs to be heavily invested in as this service is in great demand but very little night support available in the community

**Themes from comments on questionnaires**

4. Expectations of benefits it will bring – eg anything to help ease the load on a family, or make life easier for a patient who may be on their own, these services will be invaluable to carers
5. Concerns – eg about costs to patient and family, about shortage of people providing social care in a sensitive way
6. Recommendations – eg night sitting service needs to be heavily invested in, services must be dependable and easily accessed with little waiting.

**Comments/responses from public meetings and community and staff responses**

The two that responded to question 2 both supported the proposal. Comment made relating to this theme:

Response	Comment
1	Use of domestic staff in a responsible and rewarding way, as these members of staff will have daily close contact with service users and relatives. Domestic staff should have clear professional boundaries between nursing care and social care home help and support. Relatives and carers should be fully aware of the service being offered ...to resolve issues of contention between nursing and social care.

**QUESTION 3**

Question	Response	Comments
<b>Do you support the proposals to provide additional holistic (eg alternative therapies, spiritual and religious support, access to support groups) end of life care services within the community?</b>	13 YES 1 NO 3 NO RESPONSE	<p>1. Most people have their own religion. If advice needed about spiritual things their own minister should be brought in</p> <p>2. Definitely</p> <p>3. A lot of things can be gained by adopting good old methods. All these were available before the so called Western medicine arrived on earth</p> <p>4. Yes but I think access to care at home and hospice beds is more important</p> <p>5. Spiritual and religious support will have been available to people before they reached the end of life stage. They can be included in end of life services but I would not prioritise them for BENPCT. They are the responsibility of faith groups and practitioners of alternative therapies</p> <p>6. I support additional holistic therapies where it can be shown that they have a positive influence on mental health and well being. In relation to faith or spiritual support, I am against NHS funding and resources being allocated to faith groups to provide these services as it is already part of their function to provide them free of cost. The PCT does not provide circumcision on religious grounds</p>

		<p>and thus to provide faith or spiritual support paid for by the PCT would set a potential precedent</p> <p>7. There should be opportunities for individual needs to be ascertained, not only physical, practical but spiritual – and not one size fits all. However it will mean a careful and tight control in appointing professionals with appropriate status to avoid any suggestion of waste of funding</p> <p>8. Alternative therapies wonderful as long as patient/family agree. Spiritual and religious is fine only when done with care and agreement with all concerned</p>
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Online response to Q3:

All 8 respondents supported this proposal  
Comments made:

1. Christian religious support only
2. We need to assess people holistically. It is no good identifying that patients have psychological, social and spiritual needs and having no way of implementing plans to support them

**Themes from comments on questionnaires**

Some respondents made a distinction between different types of support listed under the broad banner of holistic, particularly between alternative therapies and spiritual and religious support. These people endorsed NHS funding for alternative therapies but not spiritual and religious support.

**Comments/responses from public meetings and community and staff responses**

1. Anything that puts the patient at ease will help their carers and relatives towards a feeling of confidence in the service that things are being done appropriately and professionally. The patient should make that informed choice themselves where possible.

**QUESTION 4 What sort of additional support would you like to have available for individuals in their end of life phase?**

<b>Respondent</b>	<b>Comments</b>
1	More help with district nursing, more community support <b>DN, C</b>
2	More physiotherapy <b>N</b>
3	The same care and support that Macmillan nurses give should be for all. I have seen first hand with my son how marvellous they are right to the end <b>N</b>
4	Integration with the wider community <b>C</b>
5	Visits from social services, voluntary workers and religious preachers <b>C</b>
6	More warden control facilities, less expensive accommodation, contact details of carers and accommodation, getting the message to housebound people <b>A</b>
7	Night sitters as needed, single rooms where required <b>N,A</b>
8	Hospice at home <b>N</b>
9	Dignity is very important <b>PC</b>
10	Adequate psychological and emotional support to ensure that the patient can come to terms with the end of their life but not be in a psychologically depressive nature as they approach the end of life <b>PC</b>
11	Information about every aspect of their care and treatment – being kept in the picture, opportunities to ask questions and time assured in which to do it <b>PC</b>
12	We must make sure that care is given and not overloaded with services that really are not required <b>PC</b>

Online response to Q4:

<b>Response</b>	<b>Comment</b>
1	Macmillan nurse involvement <b>N</b>
2	Equitable, adequate and appropriate support from specialist practitioners for all patients with an End of Life need whatever their diagnosis. Anticipatory prescribing of End of Life drugs to be the norm. Bridge the gap between health and social care. Rapid response team for End of Life care to prevent crisis admissions to hospital. 24/7 support and advice. The availability of appropriately trained professionals. Continued and extended knowledge and use of the Gold Standards Framework. Adequate Out of Hours Support for professional, patient and carer. Availability of more community nurses and health care assistants to provide hands on care for the patient at home <b>N PC</b>
3	I think there needs to be adequate access to emergency provision of community services. Often people/families think they can cope until suddenly things deteriorate and then they realise they need support urgently. This can happen in the last days of their life and they do not want to be rushed into hospital. There needs to be thought given to services for those with end stages dementia which is often overlooked in end of life care <b>PC</b>
4	The ability with proper legal and medical considerations and advice in

	place to choose end of life at a time of the patients choosing and not as in a case very personal to me when despite terrible pain and suffering the system was forced to keep trying to extend life to the bitter end <b>L</b>
5	It is vital to increase staffing levels and have in place a robust education programme. There is an inequity of provision. There appears to be different groups doing different things and this is fragmenting service delivery. The service needs a lead to take service forward. <b>N</b>

### Themes from comments on questionnaires

Different types of support suggested:

1. More health care staff – district nurses and Macmillan nurses particularly, but also community nurses, health care assistants and physiotherapists, night sitters. Hospice at Home.
2. Care which is patient centred – maintaining dignity, emergency planning and provision, information, psychological support
3. More integration with the local community – visits from voluntary workers
4. More appropriate accommodation
5. Legal change to allow assisted suicide

### Comments/responses from public meetings and community and staff responses

1. An intelligent review of medication for those in their end of life phase. For example, for those with only a few days or weeks to live, a reassessment of the required medication by the service user, their carer, doctor and/or district nurse could make their last days more pleasurable and less restrictive.
2. When in care, a room (culturally sensitive) where relatives could meet to say goodbye in a private and dignified way.

### **QUESTION 5 What sort of additional support would you like to have available for carers of individuals in their end of life phase?**

Respondent	Comments
1.	Training and also a lot of outside advice and help from the professionals <b>A</b>
2.	Extra sitting in service to enable carer to go out more <b>S</b>
3.	Where carers can talk to someone for advice/counselling that this type of situation brings <b>A</b>
4.	More financial support and education is needed <b>F,A</b>
5.	More flexibility with home access <b>?</b>
6.	Night sitters available as needed <b>S</b>
7.	Respite care <b>S</b>
8.	Financial <b>F</b>
9.	A complete package should be available to the carer/family pre end of life and post end of life. This should include advice and assistance on benefits, training on caring for the patient etc and support for carer or

10.	family after the patient dies <b>A</b> Checking that carers are comfortable with administering drugs bearing in mind that there are some very powerful drugs which can be supplied with no check to see that this is understood. And they may be given over a prolonged period throughout the day. Respite provision to be ensured. <b>A S</b>
11.	Make sure that carers are recognised and need help before and certainly after death of loved ones <b>A</b>

Online response to Q5:

Response	Comment
1	Specialised palliative care nurses <b>N</b>
2	Respite, sitting service, counselling as required. Access to follow up bereavement services, complementary therapies. To be listened to <b>S, N</b>
3	I think carers would like to know they can call for help at any time of the day or night <b>A</b>
4	Able to talk to people who have gone through this already <b>A</b>
5	Drug boxes, proactive prescribing, equipment in 4 hours, pre-bereavement counselling, increase in hospice at home, better information <b>A,E, N</b>
6	More respite facilities <b>S</b>

### Themes from comments on questionnaires

1. Source of advice and information, so that there is “someone they can call for help at any time of the day or night.” This could include talking to “people who have gone through this already”
2. Respite care, including sitting service
3. Financial help if needed
4. Specialist nurses
5. Equipment quickly when needed

### Comments/responses from public meetings and community and staff responses

1. The carer should be given additional support such as respite, training (for example in manual handling) and counselling wherever necessary
2. The offer of counselling and administrative support to help with inevitable arrangements following as a consequence of death

**QUESTION 6 What role could the voluntary sector play in providing support to patients and carers in their end of life care phase?**

<b>Respondent</b>	<b>Comments</b>
1	More help to patients in their own homes
2	Not left too long on their own if only to stay for short periods of time. Not all people have a family to care for them – I haven't
3	Getting people in touch with others, drop in centre just to talk
4	Quite a lot. Very little use is made of the voluntary sector. It is nice for politicians to say that everything under the sun should be provided by taxation. Idling youth could be trained to provide voluntary service
5	Advertise where warden controlled accommodation is in the area. What voluntary facilities offered
6	Supportive friendship
7	Help with the cost of transport for shopping and any hospital visiting
8	I am opposed to the increase in emphasis on the voluntary sector as the service provided by the voluntary sector can be erratic and is not subject to enough statutory control and inspection for quality and consistency
9	Dovetailing where the PCT does not have the expertise or resources eg hospice ethos or infra structure. But this should not be an escape route for avoidance of funding
10	I feel the voluntary sector could be the stability because the same person would be there right to the end, this is what people need, the same face all through the process

Online response to Q6:

<b>Response</b>	<b>Comment</b>
1	Proactive role whereby visits can be made to patient home to enable carers to have time out from the situation and generally to support the patient
2	Bridge the gaps between health and social care. Provide transport. Sitting service. Befriending
3	Respite services
4	Domestic care, shopping, gardening, pet care, advocacy
5	Sitting service providing day time respite to allow carers time to get out, befriending service

**Comments/responses from public meetings and community and staff responses**

1. The voluntary and community sector would be ideally placed to fulfil the ‘key worker’ care co-ordination
2. Support groups with optional attendance and support in person, telephone or administrative support

**QUESTION 7 How could the PCT best ensure local people with the necessary skills have access to information about the job and volunteer opportunities that would be generated through redesign and relocation of services?**

<b>Respondent</b>	<b>Comments</b>
1	More information needed – very little information given to patients of what help they can have
2	I believe nurses should be rewarded with a decent pay first. All their caring – we need them.
3	More publicity especially at community centres and work and pension offices. Employ and train the youth who are committed to do community service
4	Advertise more, flyers, open evenings
5	A simple information phone service direct to services available. Work together with all the other BCC and PCT service providers
6	Advertise in local press, local retail outlets, web pages on local internet sites
7	Advertising
8	Intensive information and publicity widely distributed via press, public sector institutions, appropriate unions, local organisations, support groups, faith groups ,social facilities, professional groups, GP surgeries, pharmacies
9	We need all sectors to come together and agree ALL would be given the SAME and correct information and whoever is in charge knows all the names of each person for a particular case

Online response to Q7:

<b>Response</b>	<b>Comment</b>
1	Advertise through the health news letter abd distributed in local health centres, GP surgeries
2	Incorporate in some way with Pan Birmingham Palliative Care Network Living Well to the End of Life. Local advertising newspapers and radio. Advertise on the Palliative Care website – accessed by patients, carers and general public
3	Proper advertising and door to door leaflet drops
4	Local press shopping centres, websites, local radio and TV
5	Advertising in local papers

### **Comments/responses from public meetings and community and staff responses**

1. Holding open days with local community leaders that influence all ethnic groups, use media, flyers. Embrace champions with whom the local community might identify to promote awareness about new job opportunities and introduce the facility to all the community
2. Engage with voluntary and community groups to provide information about the available services and encourage volunteering opportunities.

### **Other issues**

1. Existing beds should not be got rid of before capacity is built up on the community
2. It is essential that the person managing a patient's end of life care will also be able to allocate resources: this might be in terms of a personal budget for individual needs as well as the ability to call on resources from other directorates
3. Training relating to end of life care should be embedded in all staff that have contact with patients in their end of life
4. Assessment processes should be joint to avoid health and social care providers each asking patients similar questions causing distress and inconvenience
5. Health care professionals need to share patient files/information so that they follow up on things
6. Equipment if often not collected yet there is a shortage
7. Marie Curie Nursing Services would have preferred to be involved in decisions early rather than find out through the consultation that there is a proposal to disinvest in their services. Current service provision by them also appears to be omitted in the section dealing with this.
8. St. Giles Hospice is concerned that factual errors misrepresenting the type, level and cost of services provided to the community of North Birmingham by the Hospice have not been rectified.
9. How will the needs of patients with dementia be managed – where is the divide between intermediate and End of Life care?
10. There is a need for as hospice in Bordesley Green to ensure adequate facilities
11. St. Mary's hospice already co-ordinating individual care and the service is excellent
12. Facilities should be available for people with no relatives to care for them, particularly stroke patients
13. If BME groups have patients in current services /hospices they are often isolated within a non BME group and feel alone and often frightened
14. PCT needs to address inequalities not just in terms of where people live but also in terms of illness

### **Main questions asked at public and staff meetings**

1. Is the PCT trying to push palliative care out of hospitals?
2. Is the strategy being target driven particularly about the very ambitious moves to reduce the numbers who die in acute care – concern that if this is a mandatory requirement it will lead to patients either being refused admission or discharged inappropriately in order to meet the target
3. Will nurses co-ordinating care be based at GP practices?
4. How would people access community services if taken to hospital
5. Would the new strategy provide further job opportunities for the staff whose jobs are at risk under the existing management restructuring process at JTH?
6. If you are developing palliative care services, what about people who need these but are not at the end of their life?
7. Will the PCT explore deaf awareness training for staff?
8. Does this include services for children?

### **Comments on the consultation process**

1. OSC feels that overall the consultation process was appropriate although they had concerns initially about running the two at the same time but having monitored them were satisfied that a clear distinction was made between the two
2. Some members of the public dominated the discussions; slides were difficult to read.
3. Trust not proactive in establishing a way of feeding back to participants – could leave name and address
4. Need for greater clarity *“the consultation questions and consultation document were vague; nowhere in the document was the respondent asked for their preference over the three options put forward.”*